U.S. Department of Veterans' Affairs Research Advisory Committee on Gulf War Veterans' Illnesses (RAC-GWVI) Recommendation for New VA Gulf War/Era Data Report

Adopted June 27, 2011

Introduction

The VA's newly revised Gulf War era report provides a substantial advance in publicly available VA data and builds upon the former Gulf War Veterans Information System (GWVIS) reports, which were discontinued a few years ago.

The RAC commends VA staff for their diligence, commitment, and expertise in developing this new, scalable report and its underlying data set.

The RAC has adopted the following recommendations, and respectfully requests their adoption to the maximum extent possible. The RAC also encourages the adoption of consistency checks for logic in the presented data (for example, to identify and correct logical impossibilities such as data showing Gulf War veterans who, based on currently reported age, would have been far too young to have served in the 1991 Gulf War).

The current report provides a substantial advance in usable Gulf War/Era data. We hope these recommendations will only strengthen that reporting and help provide even more usable data to further our shared objective of improving the health and lives of these veterans.

- 1. RAC-GWVI Data Focus. The RAC is specifically focused on the health needs of veteran of the 1991 Persian Gulf War. The earliest of these war veterans deployed to the Persian Gulf on August 2, 1990; the majority had redeployed out of the theater of operations by about mid-summer of 1991. The VA's former GWVIS data reports used a July 31, 1991 cutoff date for the "Persian Gulf War" that, while somewhat arbitrary at the time it was selected, has since taken on a life of its own as the end date for subject inclusion for many research studies which are then compared against each other. The new report uses a cutoff date of 1992. Not only does this 1992 cutoff data no longer allow for data comparison of a long established DS + DS + post-Gulf War cohort, but it dilutes the usage, cost, ICD-9, claims and other data for the true 1990-91 Gulf War cohort.
 - a. Recommend that the report provide data for the following additional/substitute cohorts: Desert Shield alone; Desert Storm alone; Post-Desert Storm alone (Feb. 28 Jul. 31, 1991); Desert Shield + Desert Storm; "Gulf War", named as such, and defined as August 2, 1990 July 31, 1991.
 - **b.** Recommend the continuation of providing special focus data for the Khamisiyah and al-Jubayl cohorts.

- **c.** Recommend the report continue to provide data on the entire "Gulf War Era" cohort, named as such, and defined as August 2, 1990 September 10, 2001.
- **d.** Recommend the report differentiate between Gulf War Era Deployed and Gulf War Era Non-Deployed.
- **e.** Add non-deployed comparable comparison group for generally all report data, across the board.
- Regular Assessment of data needs. There are many potential non-VA users for this
 critically important VA data, with varying data needs and interests, including at least the
 RAC-GWVI, VSO's, Congress, the media.
 - **a.** Recommend that these groups be consulted annually on their data needs.
 - **b.** Recommend current proposal to provide updated data annually be implemented and maintained in perpetuity.
- 3. Title of report. The title of the report has a psychological impact on the various report audiences, including Gulf War veterans. The current title incorporating the new term "Pre-9/11" fails to recognize the Gulf War, Gulf War Era, and Persian Gulf Theater of Operations Service of those it describes. Gulf War veterans have already been offended by this lack of recognition of their service.
 - **a.** Strongly recommend that the report's title be changed to "Gulf War/Era" data, which would more appropriately recognize the service of those the report describes.
- **4. Executive Summary**. Include an executive summary of the document, which also includes:
 - **a.** The "big numbers" -- broad totals from the various report sections.
 - **b.** Compare-and-contrast between Gulf War, Gulf War Era, deployed and non-deployed, and any areas of data that appear significant, unusual, or otherwise notable.
- VA Usage. Recommend total usage -- both cumulative and current, and both number of total visits and number of unique veterans -- be shown for VBA, VHA, NCA, Vet Centers, and total VA.
- **6. Costs**. Currently, the report provides costs by VISN. Recommend this section of the report also include a nationwide total. Further recommend total costs -- both cumulative and current -- be shown for VBA, VHA, NCA, and Vet Centers.

7. Deaths.

- **a.** Recommend death statistics be included for all cohorts.
- **b.** Recommend suicide data be included for all cohorts.
- **c.** Recommend death data be provided as a cumulative total, and by 5-year time segments.
- d. Recommend death data be provided by age bracket (e.g., by decade of life) and

comparable non-deployed cohort data be provided for all data, as per 1e, above.

8. ICD-9 codes.

- **a.** Recommend data analysis be conducted and the results added to the report identifying usage of VA, VHA, VBA, NCA, and Vet Centers by ICD-9 code, particularly 8800 series (UDX) [e.g., by the top 20 ICD-9 codes]
- **b.** Recommend data be split out by sex.
- **c.** Recommend data analysis and reporting of mental health ICD-9 codes and whether they exist alone or comorbid (concurrent) with other non-mental health ICD-9 diagnoses.
- **d.** Recommend data be provided to show number of unique veterans for all cohorts with ICD-9's for ALS, MS, other neurological diagnoses, respiratory diagnoses, dermatological (skin) diagnoses, and cancers.

9. Claims approval.

- a. Recommend data be included showing UDX claims approval for all cohorts.
- b. Recommend UDX data for unique veteran and total claims approved for each UDX code, including fibromyalgia, irritable bowel syndrome and chronic fatigue syndrome.
- **c.** Recommend data be included showing claims approval for all cohorts for the "9 new presumptive" rare endemic diseases, by ICD-9 code.
- **d.** Recommend data be developed showing claims approval rates for all cohorts by trained and untrained VA Regional Offices.

10. Meeting specific data needs.

- **a.** Recommend that a process be developed to evaluate and approve requests for specific data runs of the available data, particularly, but not necessarily limited to medical researchers, VSO's, Congress, and the media.
- **b.** Recommend that a section be added to the report detailing the request process, the application or contact information to make a data request, and the parameters of acceptable data requests.